

Support Planning in Practice

When someone is offered a personal budget (PB), there are several types of decision to be made. People can choose, for instance, whether or not to have a direct payment, and there will also be decisions to make about how to get the support they need in their life. For the purposes of this study, all of that is called 'support planning'. Previous research (Williams et al., 2013a) emphasised the value gained by disabled people who access peer support from user led organisations (ULOs) while writing their support plan. However, as other authors have also maintained (Lymbery, 2012; Goodwin, 2011), some people using personal budgets have difficulties in taking control without assistance. Our study included people with learning disabilities, mental health needs, and older people with dementia.

- **The personal budget users who took part in this study benefited from help with support planning both from social workers and also from user-led organisations (ULOs) and other voluntary groups. However, commissioning of user-led organisations to provide these functions was not happening consistently, and in many cases was being withdrawn.**
- **PB users in all three groups in this study valued support plans which helped them contribute to society, as equal citizens, to pursue their creative interests, and make their own choices.**
- **PB users were satisfied with support planning when it was done in a spirit of equality and dignity. It was experienced as 'informal and friendly', while taking account of their individual differences.**
- **Those who had help with support planning from a user-led or a voluntary sector organisation tended to have good information 'up front' about the process of a personal budget. That helped them to take control, and to be flexible at a later stage.**
- **Understanding and choosing how to use a personal budget depended on clear and honest explanations and calculation of finances.**
- **Personal budget users were drawing on a wide range of community resources, but these needed better coordination.**
- **Family members were extremely prominent in this study, and had multiple roles, which often became blurred. These included the provision of direct care, as well as making decisions about the support plan, and managing the personal budget.**
- **Family members wanted more clarity about their own responsibilities in managing the budget, and about the support available.**
- **In the longer term, support plans were most successful when they were flexible, and when PB users understood that they could make changes.**

The role of the voluntary sector and user led organisations (ULOs)

Due to changes in local commissioning arrangements during the course of this study, only two of the 23 PB users in the project had support planning officially facilitated by the ULO. This change meant that ULOs were in somewhat varied positions, and some felt under threat of closure or did actually close during the study. However, the majority still carried out various functions which participants highlighted as extremely valuable. These included advocacy vis-à-vis the local authority, support to families, and the provision of peer support, activities and role-modelling for PB users.

(Voluntary organisation) were right behind us all the time, because they knew our rights, they knew how vulnerable we were as a family. (Family member)

People will be lost without (the ULO). Because some of my friends, they only have that as a network.... without it, I reckon everyone will be lost. I know that a big chunk will be taken away if it does go. A big chunk of my life and possibly me (PB user with learning disabilities)

Supporting citizenship and autonomy

People in all three of the main impairment groups in this study saw themselves as active citizens, wanting to do something worthwhile in their life for other people's benefit, and to have a support plan that enabled them to contribute to society. Their contributions included paid and voluntary work. It was noticeable that older people often wanted to pursue an interest which focused on creativity or cultural pursuits, and they appreciated a support planner who took the time to find out what their previous interests had been.

However, some local authority staff in particular had tried to dictate what was 'good for' the PB user, and that was not appreciated:

My independence, I think really is the main one. Doing what I want, rather than being told what I can't do. Just to get on with my life, really. (PB user with learning disabilities)

Both mental health service users and older people frequently said that they did *not* wish to be sociable, just because someone said it was good for them. A strategy which worked better for them was when support planners were able to break down decisions, and separate out what people wanted (their outcomes) from the actions needed to obtain them.

Informality, equality and dignity

This research showed that the interaction people had with support planners was important. Large or formal meetings did not generally work well. People said that making a decision was always something best done in relaxed circumstances, with time for reflection. For instance, one family member said that a social worker had advised her:

Look, let's not do anything quickly. Go away and think about it..." (Family member)

Both local authority and ULO support planners could create relaxed settings for decision making, with a feeling of equality and valuing of people's views. One PB user had just left a period of hospitalization, and she was overwhelmed with the 'ordinariness' of her interaction with the support planner, who simply suggested a walk together in the park:

It was lovely surroundings, it was relaxed, it was usual territory, so I didn't feel threatened that I was going into some building or office that I didn't know, it was somewhere that I did know. (PB user with mental health problems)

PB users often mentioned that they appreciated help that was sensitive to individual differences. There were several good examples of support planners working with people who had communication support needs – for instance, by offering them picture choices, and simply by getting to know them and taking time to share joint activities with them. Families from different ethnic backgrounds and their disabled relatives also benefited from sensitive support planning, which made them feel welcome, without assuming that they would fit into a cultural stereotype.

Information

Amongst PB users in this study, there was widespread confusion about what a 'support plan' was and how it fitted with other parts of the PB process. Older people and their family members were particularly ill-informed. Many people were unclear about the difference between 'assessment' and support planning, the workings of a 'validation panel', and the purpose of a review.

For people to choose for themselves how to use their budget, they needed good information about direct payments, employment and provider organisations. People also wanted to know about directly provided services, such as day centres, employment support or older people's clubs. One of the most useful means for disseminating information was through regular groups, which allowed both for peer support and networking. People with learning disabilities in one area had shared their experiences through a People First group..

Support planners sometimes usefully gave advice based on knowledge of local services. For instance, one ULO support planner had helped a PB user with mental health needs to phone around different cleaning agencies to get information. People said they liked to learn by example; knowing someone else who had used a direct payment for instance was very valuable. When asked what was most useful, participants sometimes talked about 'specific' information:

Probably more specific questions. So instead of me just answering in a broad way, to be questioned more about it. To get the specifics. (PB user with mental health needs)

Family members in particular mentioned the importance of the support planner advising on what types of item could be funded, and all the 'hidden extras' that need to go into a budget, including contingency costs.

Need for coordination of services and community activities

In order to achieve the outcomes they wanted in their lives, people spoke of different kinds of services or supports they needed. These included personal assistance in the home from people they could trust and get to know, and support to go out and take part in activities – a very common theme. Family members of older people urgently wanted better coordination of information about what was available.

ULOs played an important role here in introducing PB users to activities or groups which they may want to access, such as theatre groups or swimming clubs for people with learning disabilities. ULOs could more easily provide this type of link into the community, since their role was broader than that of a social services department. Nevertheless, there were also a few instances of social workers who were

appreciated because they were prepared to 'roll their sleeves up' and help someone to access their community. In one instance, this was a social worker who had helped a young man to go into college each morning, while he was getting used to it. Getting involved in this way, even if for a short while, helped PB users to trust that social workers really cared about them, understood their needs, and were suggesting opportunities that might be worth trying.

Family members

Eleven of the 23 participants had family members who both lived in the same house, and contributed hugely to their support. Their role was a multiple one, splitting broadly into functions that could be described as 'direct support or care' and functions related to decision making and managing the budget. Family members generally felt that good support planning could help their relative, and therefore also helped them:

I feel like I've got my life back and I feel that my daughter has grown in independence and confidence massively.(Family member)

However, at least ten family members were making decisions, receiving the budget and managing it on behalf of their relative who lacked capacity to make that decision. Family members themselves were generally unaware of their own official role as 'suitable persons' and many felt that they were not well supported in that role. For instance, they generally found that reviews were only about the finances, rather than the outcomes and goals of the PB user. Some expressed a sense of desperation:

What happens if we're not here today? What's he going to do? You tell me. He's going to – you're going to pick him up and put him somewhere where he's going to have no clue of, no experience, no knowledge. (Family member)

Those who took part in a voluntary organisation dedicated to families felt most supported.

Support planning: the longer picture

In addition to the findings presented above, we went back to twelve PB users in the same impairment groups from our previous study (Williams et al., 2013a). We analysed their in-depth stories, and found that support plans were most useful and successful in the longer term if they were flexible. People's lives changed dramatically, and they needed to have the control and autonomy to be able to manage those changes. For instance, one family of a person with dementia had moved over from agency support, and directly employed one of the existing staff members, so that their disabled relative had greater consistency in her final months and was able to stay at home. A young man with learning disabilities had obtained paid employment, and so no longer needed some of the leisure activities he had previously had in his plan.

Those who had the greatest success with their support plans told us that information about the system and about their role mattered most. When asked what had made the greatest difference to them, one family member said:

I think probably [the ULO support planner]. Giving us an idea of the sort of things we could do with it... It's nice ... having somebody to contact if you have any queries. Somebody who's been through it and knows the stages that you have to go through. (Family member of person with learning disabilities)

The Support Planning in Practice research study

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This study took place in five sites in England. We sampled ULOs or other voluntary sector organisations (VSOs) which had experience of carrying out commissioned support planning with one or more of our key target groups. They were seen as models of good practice, rather than typical or generalizable sites. Following practitioner workshops for ULOs and local authority staff, twenty-three PB users were recruited to the research either by the local authority or by the ULO, and each of them took part in between one-three semi-structured interviews.

The first set of interviews focused on people’s experiences of the process of support planning, their goals and wishes in life, while the second and third interview was about the *outcomes* of support planning and eventual satisfaction. A ‘good support plan’ was defined by PB users themselves, or in nine cases by their family members on their behalf. We also gained permission to directly observe and/or record support planning meetings for three participants.

We were also able to re-interview twelve PB users from a previous study for the Office for Disability Issues (Williams et al., 2013a), thus providing an additional longitudinal strand to the current research and one further site. Details of the groups represented are given in Tables 1 and 2. Family carers were prominent in the data, taking part in of 11 of the 23 interviews in this study, and a further 8 of the additional 12 interviews. In ten of these families, we carried out ‘proxy’ interviews with family members, but always asked to meet and spend time with the disabled person as well.

Table 1
Details of participants¹

	A: Social services support plan (no ULO or VSO support)	B: Social services support plan (ULO or VSO general support to user)	C: ULO or VSO helps service user write their own support plan	D: Service provider helps person to plan their support	Totals
People with learning disabilities	4 (+2)	8	4 (+3)	0	21
People with mental health needs	0 (+1)	2	2 (+3)	0	8
People with dementia	0 (+1)	0	0 (+2)	0	3
Age-related supports	0	0	0	3	3
Totals	8	10	14	3	35

Further details of the study can be obtained from: Val.williams@bristol.ac.uk

¹ The 23 participants from the current study are given in each box, followed by the number re-interviewed from the ODI study in brackets.

Publications

Williams, V., Porter, S. and Strong, S. (2013) The shifting sands of support planning. *Journal of Integrated Care*, 21 (3): 139-147.

Williams, V., Porter, S. and Strong, S. (2013b) *Speaking up about your support plan*. DVD about support planning for people with learning disabilities.

Williams, V., Porter, S. and Strong, S. (2013c) *Planning your own Support*. A booklet for people using personal budgets.

References

Goodwin, N. (2011) 'Can older people with cognitive impairments make effective choices about their health and social care? A commentary on Meinow, Parker and Thorslund from an English perspective', *Social Science and Medicine*, 73: 1290–1.

Lymbery, M. (2012) 'Social work and personalisation', *British Journal of Social Work*, 42(4), pp. 783–92.

Williams, V., Porter, S. and Marriott, A. (2013a) Your Life, Your Choice: Support Planning Led by Disabled People's Organisations. *British Journal of Social Work* (2013): 1-19. doi:10.1093/bjsw/bct005

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